



Canadian Addison Society **La Société Canadienne** **d'Addison**

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Issue No. 16

Addison Info

April 1999

President's Message

I am writing this message at the request of our president, Mrs. Greeta Fraser, of Trenton, Ontario.

She is under a great deal of physical and emotional stress at this time. Her husband of many years, George, who was critically ill, suffering from the effects of advanced cancer, passed away on the third of April.

I know that we all will want to send her our thoughts, messages and prayers at this very difficult time in life.

Greeta was one of the founding members in the formation of the Canadian Addison Society. We owe her a great deal for all her time, effort and devotion, and many of us will want to pass on our thoughts, our concern and our love. For those that may wish to write, Greeta's address is:

25 Elizabeth Ave.
Trenton, ON
K8V 2R1

Greeta asked that donations be made to the Canadian Cancer Society or the Heart and Stroke Foundation.

Thank you,
Joan Southam



The Start of the Canadian Addison Society

It was 1989. Greeta Fraser lived in Lindsay, Ontario and I, Sybil Harrison, lived in Montreal. We were both waiting for a train in the Montreal Station. I was going to Toronto and Greeta was going to Nova Scotia. We started talking and Greeta mentioned that she had been ill, so I asked what was wrong and she said that she had Addison's disease. I couldn't believe my ears; prior to that time, I had only met one other Addisonian. I told her that I had Addison's disease for the past 35 years. Meeting somebody else with Addison's helped Greeta feel a lot better.

We exchanged addresses and started to poke around for other Addisonians. We had a couple of meetings and look where we are today.

The only other Addisonian I knew could not relate to me and when she saw me, she said that I looked too well to have Addison's disease. I figured that she needed more help than I could give her so decided to ask "Ann Landers" for advice. Ann Landers sent me the NADF address as there was no group in Canada. They sent me a couple of names of other Canadian's with Addison's. It's amazing what one letter and one chance meeting can do.

Thank you to Sybil Harrison.

Upcoming Meetings and Contacts

Vancouver Canadian Addison Society – July 10

1:00-3:00 pm, Sherbrooke Lounge, Sherbrooke Centre, 330 E Columbia St., New Westminster. The building is at Royal Columbian Hospital site corner of Sherbrooke and Columbia Street.

Endocrinologist, Dr. Kendlar will be the guest speaker. The focus will be on osteoporosis. Questions for Dr. Kendlar can be e-mailed to Catherine at SempleC@em.agr.ca or call Judy.

Contact Judy Stanley (604-936-6694) (bugbee@direct.ca) for further information.

Next meeting – October, tentative guest speaker is a Nutritionist

Vancouver Island Support Group – May 8

1:00 pm, Victoria General Hospital, Room 1814.

Marjorie Moulton, a Chinese Medicine Practitioner and a member of the Vancouver Island Support Group has agreed to talk about an alternative approach to managing some of the stresses associated with Addison's.

Contact Jim Sadlish (250-656-6270) (wx699@victoria.tc.ca) or Florence (fmweekes@mail.islandnet.com)

Alberta Addison's Support Group – Fall of 1999

Contact Peter Little (780-922-5307) (litt019@ibm.net) or Ginny LaValley (780-939-3730)

Eastern Ontario – May 1

Around 12:30 pm, an informal lunch is being planned at Robbie's Italian Restaurant, 1531 St. Laurent Blvd. (Ottawa's East end). Please confirm with Elaine.

Contact Elaine Hall (613) 824-0160 (grahamhall@sprint.ca)

Southern Ontario – May 8

1:30-4:00 pm, Brantford Police Station at the corner of Elgin Street and Wayne Gretzky Parkway.

The speaker, Dr. Gene Jarrel, is the head of Emergency Services at the Brantford General Hospital.

Besides speaking on the Emergency 'experience', he will also answer questions that we have given to him about general emergency concerns.

Contact Joan Southam (519-753-1271) (jsoutham@home.com)

Quebec

Unfortunately due to time constraints, Sophie will no longer be the contact person for Quebec. If you are interesting in taking over as the contact person, please contact Joan Southam.

If you wish to start a support group in your area, please contact Joan Southam at the Canadian Addison Society for information, guidelines or supplies that may be of assistance. Joan can be reached at (519) 753-1271 or e-mail: jsoutham@home.com



Meeting Notes

Vancouver Canadian Addison Society – March 13

19 attended of which 12 had Addison's or Cushings.

Unfortunately the planned speaker cancelled at the last moment but the group discussed osteoporosis and medications.

One of the attendees has a child with Addison's and would like to hear from other parents in the same situation. Contact *Judy Stanley (604-936-6694)* (bugbee@direct.ca).

Vancouver Island Support Group – February 6 & 24

The meeting on Feb. 6 had 14 in attendance. 8 with Addison's, 2 with pituitary dysfunction and 4 concerned relatives.

The hour meeting stretched beyond 3 hours with the group comparing experiences with everything from different drugs, symptoms, reactions, diets and supplements, to different attitudes on the part of physicians. The greatest patient satisfaction came from relationships with doctors who make treatment a 'team effort'. There was general agreement that the most important non-drug treatment for an Addisonian is rest.

The meeting on Feb. 24 had Dr. C. von Westarp, an endocrinologist, as the guest speaker. Topics of discussion included replacement medication preferences, an explanation of 'half-life', DHEA, and emergency syringes. 13 people attended this meeting.

It was noted that DHEA should be avoided until definitive scientific studies prove it to be safe.

Jim is in contact with the Product Manager at Organon Teknika for information on the Hexadrol syringe. He will let us know when he has something further to report.

Alberta Addison's Support Group – March 6

10 attended, 9 with Addison's.

Dr. Jody Ginsberg, an endocrinologist, was the guest speaker. He focused on the composition and hormone output of the adrenals. The different tests used for diagnosis of both primary and secondary Addison's Disease; as well as the clinical features of acute adrenal crisis.

Southern Ontario – February 6

Dr. Sandy Kunej, a local chiropractor in practice since 1995, was the guest speaker to the 33 in attendance.

He provided an overall picture of what chiropractic medicine is today, its history and his philosophy regarding health and wellness.

There are 5 main principles:

1. Your body is a self-regulating, self-healing organism.
2. Your nervous system controls and coordinates the function of every system, organ, tissue and cell within your body.
3. Interference to your nervous system, most commonly caused by vertebral subluxations (corrections to interference with the nervous system); obstruct/alter the flow of nerve impulses, thereby weakening each organ or tissue, making it more susceptible to illness and disease.
4. Specific spinal adjustments correct vertebral subluxations, thereby maximizing nerve flow and optimizing your health potential; and
5. Doctors of Chiropractic Medicine are the only health care professionals educated & trained to detect and correct vertebral subluxations.

Chiropractic medicine was a Canadian discovery by B.D. Palmer from Port Perry in 1895. The profession has been certified since the late 1960's.

Announcements

Dorothy Fewing, an Ontario member passed away while awaiting surgery.

The Canadian Addison Society has donated \$50.00 to the Cancer Society on behalf of Greta Fraser.



Ask the Doctor

D. Killinger, MD, PhD, FRCPC

Thank you to Dr. Killinger for taking the time to respond to our questions.

- Q.** Is congenital adrenal hypoplasia (CAH) the same as Addison's Disease?
- A.** CAH is an uncommon problem in the development of the adrenal due to an abnormality on the X chromosome. It presents either at birth or shortly after with salt loss and failure to thrive.
- Q.** After several years of being treated for Addison's Disease, one of the CAS members was told by a specialist that it may be Simmonds' Disease. What is that?
- A.** Simmonds disease is secondary adrenal insufficiency. This means that the adrenal problem is due to a lack of ACTH from the pituitary rather than a problem in the adrenal gland itself.
- Q.** In secondary Addison's, do they replace the ACTH hormone as well as the cortisone therapy?
- A.** No, the effect of ACTH is to stimulate the adrenal to make cortisol. Since we are replacing the cortisol, there is theoretically no need for ACTH. To replace ACTH, we would have to inject it either many times per day or daily, depending on the preparation. The tablet approach is felt to be more convenient and more effective.

Should you have questions which you would like to have forwarded to Dr. Killinger, please send them to Joan Southam.

Equivalent Dosages

Dose	Steroid	Relative Potency
20mg	Cortisol (hydrocortisol)	1
25mg	Cortisone acetate	0.8
5mg	Prednisone	4
4mg	Methylprednisolone	5
0.5mg	Dexamethasone	25

Enjoy Your Food

Small changes for healthier options.

The following methods of preparation and serving of foods can help to make popular foods healthier.

1. Grill or bake fish and meat instead of frying.
2. Boil or bake potatoes instead of frying or roasting.
3. Try stir-frying meat or vegetables using only a little oil.
4. Eat a spoonful more pasta and a spoonful less sauce.
5. Use reduced fat milk in sauces, and fromage frais or plain yogurt in place of cream.
6. Serve salads or vegetables and bread with main meals.

(From the Addison's Disease Self Help Group (ADSHG) by Deana Kenward from the UK)



Personal Glimpses

Sybil Harrison - Quebec

I have been an Addisonian for almost 45 years, since April 1, 1954. I was very fortunate to have a G.P. who studied all his text books until he figured out what was wrong with me and sent me to an Endocrinologist within five days. (I looked Addison's Disease up in an encyclopedia, which said it was usually fatal within a year). Cortisone had only been on the market five years at that time. The Endo was amazed to think a G.P. would properly diagnosis Addison's Disease. I was hospitalized for a week to get my dosage stabilized, and it was decided I needed 75mg of Cortisone Acetate daily (25mg 3x/day).

Two years ago when I saw Dr. Killinger, I thought he was going to have a heart attack when I told him what I was taking, but I am still on the same dosage today. He decided that it was to late to change the dosage. Two other Endos tried to cut down the dosage but it did not agree with me and as soon as I returned to 75mg, I was fine. Now I refuse to change. I have never taken Florinef but I do use a lot of salt.

I was diagnosed when I was 30 years old. At that time I had a seven year old daughter and a six year old son. By September 1994 my menstrual cycles stopped and I never had a problem from then on.

In 1953 I had returned to work because I had both my mother and mother-in-law living with me. (Who needed three women running one house?) They were both with me for over 25 years. I am now 75 years old and still work one day a week as a Manual Bookkeeper. I am a widow nearly 24 years, live on my own, drive a car, travel, play bridge, and do volunteer work.

My purpose in sending my story is to let others know that I am one of the most fortunate people alive. I always claim that if I have to have a disease, Addison's is easy to live with. Over the years I have developed an underactive thyroid and take 0.088mg Synthroid every day. In 1968 I developed complete alopecia and therefore have lost every hair on my head and body (there is nothing to be done for that). About two years

ago I developed pernicious anemia and now go for a B-12 injection monthly. But none of the above cause me any pain or stop me from leading a normal life. Until four years ago, I was not even aware of an Addisonian crisis; so you can realize how lucky I am as I have never experienced one.



When I read some of the Addisonian stories, I can only wish others can live a normal life and enjoy a normal lifestyle.

Ginny LaValley – Alberta

Hi, my name is Ginny LaValley and I will relate my experiences with Addison's Disease in the hope other Addisonians will share their experiences with me. In 1991 my health was not as it should be. For six months I was having intestinal problems that would not clear up. It was affecting my full-time work and family obligations, not to mention feeling generally "yuk"!! I had every imaginable test with no conclusive results.

In 1992 I began to have some unusual things happen to my body – most notably my skin color. I became very tanned looking even though I had minimal exposure to the sun. My elbows were very dark, as well as the palms of my hands and the nape of my neck. I mentioned the darkness of my gums to my dentist. His response was, "Well, not everyone has light pink gums". I mentioned that the present color of my gums was not the color they were before. He seemed unconcerned and unwilling to continue the conversation.

In the meantime I was experiencing extreme weakness in the morning, nausea all day, intestinal problems, lack of appetite, tiredness, and loss of weight (a general feeling of malaise).

At the beginning of 1993 during an annual check-up, I again mentioned my concern about my dark skin colour. The doctor felt it was nothing to be concerned about, but that if I felt it was necessary he would refer me to a dermatologist (this all takes time, of course). I saw the dermatologist in April of 1993, he noted the skin darkened areas and said that he had an idea of what may be

causing it and referred me to an internist. I saw the internist shortly thereafter and he ran numerous tests confirming that I have Addison's. He discussed it with me (although not in depth) and prescribed hydrocortisone and florinef. He stressed that I should fill this prescription immediately and begin the medication immediately. He asked if I preferred to see an endocrinologist as my doctor and I said "yes". At the time of diagnosis I weighed 103 lbs, 22 pounds lower than my healthy, normal weight. Upon starting the medication, I felt stronger and much better almost immediately. I stayed stable on the medication until my marriage broke up in 1995 (after 28 years) and went into divorce proceedings. I quickly learned that stress is not favourable to an Addisonian, and doctors can make mistakes. My endocrinologist put me on the steroid Decadron to help my body cope with the added stress. This is a very strong steroid and as a result of its use, I developed Cushings Syndrome and all the unpleasantness that goes with it. My GP had never agreed with the endocrinologist's prescribed medication, which left me very uncertain as to who I should listen to. My point is that we, as Addisonian's, need to be as informed as possible about both our disease and the medications that are prescribed for us. For the past year I have been seeing a different endocrinologist and am pleased with him – he is willing to take the time to answer questions and is willing to hear what I have to say about anything new I may have learned about Addison's.

Because Addison's is a rare disease, it can be very frustrating to find somebody to talk to about it, other than your doctor, who may or may not have or take the time the time to discuss things in depth. This is why it is so important for us to have contact with other Addisonian's through the Canadian Addison's Society, the Canadian Organization for Rare Disorders (CORD), and the National Adrenal Diseases Foundation (NADF) from the U.S. We can be supportive of each other and exchange the newest information that is out there.

Speaking of new information, I saw my endocrinologist recently and mentioned that I felt my medication (Nova Prednisone) was too high a dosage for me. The indications were weight gain, fat deposits on my face, neck, collarbone area, and facial hair

growth. He mentioned receiving information on a study which indicated a prescribed dosage of hydrocortisone (Cortef) of 10mg/5mg/5mg per day as being adequate to maintain a healthy level. I have now been on that dosage for 3 months and am feeling very well. This is not to say it would work the same for all Addisonian's.

I also take Fosamax, which helps to build bone density (which we lose through the use of steroids). I have been on Fosamax for just over a year and recently had a bone density test done and the medication is slowly working! That's good news!

In closing, I will say "let's stay in touch with each other, and pass on our experiences and information!"

Take care and stay well! **Ginny**
P.S. Does anyone else have problems with weight fluctuation? I have a 'skinny wardrobe' and a 'fat wardrobe'.

Addison's Disease gets National Exposure

On January 18th Dr. Becker (Ted Danson) diagnosed a case of Addison's disease on the sitcom TV show "Becker".

The show depicted a patient who was exhausted for over six weeks. Dr. Becker ran every test he could think of. Near the end of the program, an office assistant noted the man worked indoors yet had an incredible tan, this was what 'tipped-off' Dr. Becker.

Speaking of 'Tans'...

My son is a Baptist minister and when he was ordained I still had a lot of the bronze tint to my skin. His first church was a black congregation in Nova Scotia. He was ordained in St. John, New Brunswick and the choir from his former church were invited to sing at the service.

After the service there were refreshments and a social time. I was at the lunch table when a lady from the St. John church told me, "we so enjoyed your music". I thanked her and tried not to laugh. My son really enjoyed the joke.

Thanks to Greeta for sharing this humorous anecdote.

British Study

“An assessment of optimal hydrocortisone replacement therapy” by T.A. Howlett is cited in *Clinical Endocrinology*, 1997; 46(3):263-8.

The conclusion was that most patients require thrice daily hydrocortisone. The most physiological replacement regime is achieved with a starting dose of 10mg on rising, 5mg – noon, and 5mg – early evening, adjusted to the lowest dose that maintains optimal replacement levels.

The data on the hydrocortisone day curves of 210 patients over a 9-year period were analyzed to compare 2 doses/day with 3 doses/day regimes and also to determine the optimum dosage for replacement by comparison with healthy individuals.

The abstract can be accessed online at: <http://www.ncbi.nlm.nih.gov/htbin-post/Entrez/query?uid=9156032&form=6&db=m&Dopt=b>

The author, Trevor A. Howlett, M.D., FRCP works at the Dept. of Diabetes and Endocrinology, Leicester Royal Infirmary, Leicester, LE1 5WW, UK.

Thank you to James Sadlish for this information.

NADF Conference

The National Adrenal Diseases Foundation (NADF) conference, to be held in conjunction with the National Organization of Rare Diseases (NORD), will be held Sept. 30 – Oct. 3 in Washington, DC. This will only be the second conference ever held for adrenal diseases (the first was in Oslo two years ago).

For more information contact the NADF (NADF@aol.com). Their most recent newsletter has some interesting articles on longevity with several writing who were diagnosed in the late 1940's!

Dial-a-Dietician

For dietary information, call 1-800-667-3438.

Osteoporosis Society of BC

For osteo information, call 1-800-363-1933.

Thank you to Judythe Stanley for the information on the NADF, as well as the numbers for the dietary and osteo information.

Editor's Message

Learn as you go. In the January CAS newsletter I had requested input from readers but I had not included any contact information, so here is where I can be reached:

Francisca Swist
9720 Riverside Drive
Edmonton, AB T5N 3M6

Fax: (780) 482-5016 or

E-mail: (780) swist1@aol.com

I look forward to hearing from you.

There is always room for improvement, so any comments or suggestions regarding the newsletter would be welcome.

I would also appreciate receiving your Addison's related story (perhaps how long it took to be diagnosed, or something about the physician who went that extra mile for you, maybe a humorous anecdote that you would like to share) any input would be welcome. Space permitting, everybody's input will be included. Thank you in advance.

Kind regards,
Francisca

Information provided in the Canadian Addison Society's newsletter offers a forum for personal experiences and topics of interest to Addisonians. Information should not be considered as medical advice and therefore any medical decisions should be made in conjunction with your physician.



Websites

A listing of websites offering information on Addison's Disease and related topics. Italicized headings indicate a 'new' site. Please let us know if you have an interesting site which could be included in our list (or if a URL is incorrect).

ACIF (Addison and Cushing International Federation) of Holland.

<http://www.spin.nl/nvap0302.htm>

Addison's Discussion Board. This is a new site set up by a woman from New Brunswick with Addison's. She has been through a lot and is now able to share with others.

<http://www.insidetheweb.com/mbs.cgi/mb310405>

The Addison's, Schmidt's, Cushing's and other Related Autoimmune Diseases Support Forum
This forum is dedicated to the freeflow of information, experiences, questions and answers related to Addisons, Schmidts and other similar autoimmune diseases.

<http://www.healinglight.com/addisons/>

American Autoimmune Related Diseases Association (AARDA). A non-profit association bringing a national focus to autoimmunity, the major cause of chronic diseases.

<http://www.aarda.org>

American Botanical Council. Herbal medicines.

<http://www.herbalgram.org/>

Australian Addison's Disease Association Inc.

<http://www.addisons.ml.org/>

BioScientifica. Services to biomedical science which includes the European Journal of Endocrinology online.

<http://www.bioscientifica.com>

Combined Health Information Database.

<http://chid.nih.gov>

Countway Library of Medicine (Harvard School).

<http://www.countway.harvard.edu>

Cyndi's Addisons Disease and Adrenal Insufficiency Board. A new bulletin board started and maintained by a Canadian woman.

<http://www.insidetheweb.com/messageboard/mbs.cgi?acct=mb310405>

Endocrine Web - Endocrine Disorders and Endocrine Surgery. A site written by doctors for patients. Although the site on Addison's Disease is coming soon, there are other hormone related problems discussed, as well as pictures of the various glands and their locations.

<http://www.endocrineweb.com>

Health Answers. A user-friendly site that provides additional information on items such as the ACTH test through hyperlinks. Go to Search area, select "Endocrine System" and then "Acute Adrenal Crises".

<http://www.healthanswers.com>

Institute of Medical Technology – a Finnish study project dealing with rare diseases, specifically Addison's Disease. The site offers a discussion forum.

<http://www.uta.fi/laitokset/imt/addison/index.html>

Joan Hoffman's site. Joan is the editor of the Addison News Newsletter from Michigan.

<http://www2.dmci.net/users/hoffmanrj>

Karolinska Institutet from Sweden has "MeSH (Medical Subject Headings) Classified" Resources on the Internet for lay persons, health care professionals and researchers. Scroll down and access the "Endocrine Diseases" site.

<http://www.mic.ki.se/Diseases/index.html>

Mayo Clinic Site

<http://www.mayohealth.org>

National Adrenal Diseases Foundation (NADF)

<http://medhlp.netusa.net/www/nadf.htm>

National Institute of Diabetes and Digestive and Kidney Disease (NIDDK).

<http://nidk.nih.gov>

National Institute of Health (NIH). Includes a 9-page booklet "Managing Adrenal Insufficiency" which has 4 pages, with pictures, on how to give yourself an injection.

http://www.cc.nih.gov/cccpatient_education/ai/aifinal.html

New England Journal of Medicine. For those of you with an understanding of medical terminology. Articles are available but occasionally with a cost.

<http://www.nejm.org>

Rosenthal Center for Complementary and Alternative Medicine

<http://cpmcnet.columbia.edu/dept/rosenthal>

RxList – The Internet Drug Index. An excellent reference site to check out the properties and side effects of medications.

<http://www.rxlist.com>

Skip Howell's bulletin board. An e-mail listserv. After joining you receive e-mails from people on the list. The bulletin board is divided into two topics, Addison's and All. To subscribe to the bulletin board, go to

addison's@home.ease.lsoft.com and in the text write "SUBSCRIBE ADDISONS" followed by your name.

Society for Endocrinology. Full-text online journals.

<http://www.endocrinology.org>

WebDoctor – a comprehensive index of medical resources on the Internet produced in Canada.

<http://www.gretmar.com/webdoctor>

Stress?

Do you believe that stress may have been a factor in the onset of Addison's Disease? Stress seems to be a common factor for a number of Addisonians. I was wondering whether you can recall a stressful event which occurred prior to your diagnosis? I would be very interested in hearing your story.

Suggestions?

If you have any suggestions for specific topics in the Canadian Addison Society newsletter, I would like to hear from you. Or perhaps you would be interested in writing a column on an Addisonian related topic. Your input is important and always welcome. Thank you and I look forward to hearing from you.

Just a reminder

1999 membership's are due on the 1st of January and the cost is \$20.00 per year. To ensure that we have your most recent information, please complete the following renewal form and return with your remittance if you have not already done so. Please do not miss the next copy of the Canadian Addison Society newsletter!

New Membership or Renewal Form (please print clearly)

Name: _____

Address: _____

Postal Code _____ Telephone _____

E-mail Address _____

If you do NOT want your name to be added to the Canadian Addison Society list to be made available to other Addisonians in your area, please indicate here

Please send cheque or money order payable to:

The Canadian Addison Society
c/o John Gordon, Treasurer
88 Eastwood Road,
Toronto, ON M4L 2C8